OUTCOME MEASUREMENT: THE KEY TO ACHIEVING VALUE BASED HEALTH CARE AND POSITIVELY SHAPING TEAM DYNAMICS IN INFLAMMATORY BOWEL DISEASE

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To the incredible faculty, friends, and family who made this possible:
thank you for your encouragement, support and wisdom throughout this process. I will carry the important lesson with me: measure what matters most.

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ABSTRACT

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Title: Outcome Measurement: The Key to Achieving Value Based Health Care and Positively Shaping Team Dynamics in Inflammatory Bowel Disease

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Through a small, highly selected sample, this work explores the possible effects of systematic outcome measurement on team dynamics and culture and analyzes its position within the framework of Value Based Health Care (VBHC). Six interviews were conducted with international Inflammatory Bowel Disease (IBD) specialists who do and do not systematically measure outcomes. After literature review, it was anticipated that the groups who did measure outcomes would report experiences of increased communication, a more inclusive definition of an IBD care delivery team, a more defined concept of success, and an increased sense of work satisfaction or diminished burnout. Analysis of the interviews indicated that there may in fact be a relationship between outcome measurement and team dynamics, which paralleled what has been described so far in supporting literature. This research indicates outcome measurement is imperative to achieving VBHC and care delivery improvement.

TABLE OF CONTENTS

CHAPTER 1- INTRODUCTION

1.1 High-cost, Low-yield in Health Care

The benefits of modern medical care have advanced the health of populations around the world but have also increased health care spending [1]. There is global interest in improving health care delivery [2] [3], yet a paradox of inappropriate care. In most high-income countries, health-care costs are increasing with little or no improvement in population-based outcomes [4]. Costs have raised concern across the political spectrum, as the magnitude and scope of the waste is overwhelming. In 2010, the US Institute of Medicine estimated the annual excess cost from health care waste in the United States at US $765 billion— with at least $55 billion in missed disease prevention and $210 billion in unnecessary services [5]. Inappropriate care is a widespread occurrence in which inexpensive, effective interventions are underused [6] [7] and ineffective but familiar, convenient services are overused, despite potential harm [8][1] , driving poor care around the world [9][1] [10] . Underuse and overuse occur independently of the payment system, [4] [11] and can affect the same country, health organization, hospital, and even the same patient.

The need for a high-value delivery system is established by "high and rising costs, frequent errors, unacceptable rates of infection, wide variation in process and outcomes, ethnic disparities in care, and insufficient prevention of disease progression" despite the amazing technology and wealth of the United States [12]. With so much potential for excellence, this is the core issue that motivates systematic healthcare learning and improvement centered around the need for measuring the outcomes that matter most to patients. Outcome measurement is about checking the results of care from the perspectives of both patients and clinicians, tracking whether patients were helped with issues for which they sought health care, and including the qualitative factors

integral to good care that are not always captured by process metrics. Outcome measurement can ask patients about symptoms and how they affect his or her daily life, tracking these responses over time along with when and how care was delivered. With systematic recording and centralized data, these responses can demonstrate meaningful patterns that can shape effective treatment guidelines, promote clinical learning, improve patient health, minimize waste [12], reduce burnout, and increase effective communication.

Many patients feel that their doctors must already be measuring outcomes through their patient record. While some outcomes are recorded on these charts, along with process metrics, these outcomes are not standardized across practices, there is no consensus on their importance to patients, and there is often no central collation of the data from individual reports. The health statistics that are recorded and centralized are often process measures that are captured through current fee-for-service models that record which services and treatments were provided. Process measures reflect the processes of medical care, including the specifics of diagnosis, treatment, referral, and prescribing. It is key to note here that both effective and ineffective treatment for patients incurs cost, but ineffective treatment can cause harm and require continued treatment, and continued cost. For this reason, it is important to focus on the causes of cost and how to address the causes in order to minimize cost.

1.2 Value-based care

Improving this relationship between outcome and cost is the central aim of value-based care. Specifically defined by Teisberg and Porter, in *Redefining Healthcare*, high-value care delivery is the health outcome per dollar of cost expended. This definition expresses that health care improvement requires increased medical excellence through focusing in on the results that matter

most to patients, and largely reducing the need for treatment. In this line, high-value care delivery is defined "by avoiding the need for care, or by succeeding with early-stage care in ways that reduce the need for more acute care or the amount of long-term disability" [13]. This is particularly the case in chronic conditions such as Inflammatory Bowel Disease where value is based on appropriate adherence to guidelines, effective patient communication, and trying to bring the patient as close to a normal life as possible in a cost-effective manner [14]. Patients come to the clinic because of their symptoms, so it is important to use those symptoms as a measure of value, alongside the biological markers that indicate them. While biological markers are important in giving quantifiable comparisons of patient symptoms and often reflect patient symptoms, not all symptoms have a corresponding marker. This means that patient symptoms drive both spending and patient perception of health and should be the focus of care, with the aid of process metrics and biomarkers. As care delivery makes up 93% of United States health care spending, it is imperative to focus on care-delivery where there is a large margin for improvement [12].

Approaches to care delivery within value-based care are multifaceted and include outcome measurement, quality and safety of care, team communication and motivation, and integrated care, as well as cost-effectiveness. Factors such as practitioner-patient communication, team communication and culture, team efficacy, patient outcomes, process for determining treatment, and process for treatment delivery are all integral components of both team work and value. The clinicians who deliver health care to the patient compose the care team, the members who shape the culture and performance of the group. Outcome measurement brings together these facets of care delivery as a means of organization that emphasizes the importance of practitioner-patient communication and team communication. Organization and function have a natural reciprocity,

meaning that patient-centeredness and team culture influence one another. Research shows that the culture and dynamics of such a team can have a large impact on its effectiveness [15] in treating the patient, and that higher team effectiveness is associated with better health outcomes [16] [17] [18]. This means that patient-focused organization through outcome measurement can shape team dynamics and culture to benefit not only the patient, but also the team. Much research in outcome measurement focuses on finding consensus on and tracking measurements as well as improving patient results, but emphasis should be brought to the effects of outcome measurement on team dynamics and culture. Outcome measurement may serve as a means of focusing teams in a way that makes them more effective. Teams that focus on care delivery and patient outcomes can have different communication dynamics than teams that do not systematically measure outcomes.

1.3 Outcome Measurement in Value-based care

Outcome measurement is the most effective tool in achieving value-based care because it simultaneously shapes effective treatment guidelines, promotes clinical learning, improves patient results, minimizes waste [12], reduces burnout, and increases effective communication. Accurate measurement of health outcomes is the first step in achieving value in health care [19] and is supplemented by other components including transparent reporting of outcomes and subsequent improvement of care delivery in an organized fashion centered on as single disease, as well as financially incentivizing value. While outcome measurement has shown to be effective in improving outcomes, and continuing research helps to develop and standardize measure sets, the benefits of outcome measurement for teams regarding burnout, learning, and cost still require more emphasis. This lack of information, alongside unfamiliarity with how to implement

necessary infrastructure, lead change, and amass resources, as well as a lack of confidence in newly created measure sets, and distrust on the uses of data collected from measurement, has thus far prevented outcome measurement from becoming mainstream culture in medical practice.

As measuring and comparing outcome data is the most important component of shaping practice guidelines and team and practitioner-patient communication, it is important to define which outcomes lead to this improvement. Not all outcomes are equal, and in some respects, the world of outcome measurement is still in the process of defining which outcomes both matter most to patients and the minimum number of them necessary to guide clinicians on how to treat patients. Measure sets containing agreed upon questions and outcomes for patients with Inflammatory Bowel Disease have been made independently by organizations around the world like the Crohn's and Colitis Foundation of America and the European Crohn's and Colitis Organization. While these independent sets share many of the same agreed upon outcomes and questions, they do not overlap entirely and may be difficult to compare. For this reason, groups like the International Consortium for Health Outcomes Measurement (ICHOM) have created internationally agreed upon measure sets so that results can be compared globally. Patient symptoms and outcomes are disease dependent, and ICHOM has developed standard sets for a large majority of the global disease burden [20]. With such an international effort, comes the ability to compare, communicate, and learn world-wide.

1.3 a A Case Study of Implementation of Outcome Measurement

Medical excellence can take place anywhere in the world and is not a local phenomenon. This means health care providers can ensure best care for their patients through international communication about health outcomes measures. Texas Children's Hospital in Houston serves as

one such example. The journey towards success began in 1995 when Dr. Charles D. Fraser, Jr. was recruited to lead the Texas Children's team. He recalls there being no database to compare the mortality rates of pediatric congenital heart surgery at Texas Children's Hospital to that of other hospitals. Through literature research, Fraser found that a consortium of 40 academic medical centers, not including Texas Children's, reported an average in-hospital mortality rate for pediatric congenital heart disease at 43% between the years 1983-1993. The mortality rate at Texas Children's in the early 1990s was 100%. Dr. Fraser concluded Texas Children's patient outcomes were behind those of national centers and so began recording mortality and intraoperative process measures through communication with peers at the Royal Children's Hospital in Melbourne, discussing the results with his team and ways in which they could improve. Through this process Texas Childrens' eventually ranked #2 in U.S. News and World Report for pediatric care and heart surgery. While the U.S. News and World report ranking was not outcomes-based, it was a strong indication of the positive reputation built on outcomes, which in this case was survival. The shift in focus towards patient outcomes altered the team dynamic towards communication within the team and with other teams and led to a structural change that designated and collocated pediatric cardiac surgery personnel and formalized the group as a heart center in 2001. This case study is a testament to how outcome measurement improves care and shapes team dynamics to reach excellence. Integral to this success story is the collection, communication, and analysis of health outcomes locally and internationally.

1.3 b Why Outcome Measurement is the Most Important Tool for Practicing Value-based Care

The mission of value-based health care is defined as providing capability, comfort, and calm to the patient [19]. Capability indicates that the patient can participate in the activities that are important to her. Comfort addresses whether or not, the patient is in pain, and if so, to what degree. And, calm means that other parts of the patient's life are not disrupted or inconvenienced through her pursuit of good health, as she feels she has control and consistency within her treatment. Outcome measures track capability, comfort, and calm and are integral to health because teams cannot manage what they do not measure. Without effective measurement, care has little chance of improving [21] [22] [23]. In other words, health care needs all aspects of improvement, but outcome measurement is crucial to directing growth and learning in a systematic and meaningful way, to know whether or not the changes made were effective for patient care. In addition to this central reason, outcome measurement is foundational in serving as a communication platform for both patients and providers that ensures treatment toward results that matter to patients. Similarly, the systematic organization of data serves as a learning tool by facilitating comparable results that consider both clinical and patient results. Equal to improving patient results, outcome measurement also improves physician job satisfaction by refocusing team's definitions of success to: "minimizing the impact of disease on patient's daily life" and knowing that their treatment helped patients. Outcome measurement works for both the patient and the provider to achieve their mutual goal. This thesis argues that the culture and working dynamics of health care teams directly affects and is affected by its communication and focus on delivering high-value healthcare and that these factors can contribute to both patient and physician satisfaction.

CHAPTER 2- BACKGROUND

This thesis considers the working dynamics and cultures of international Inflammatory Bowel Disease specialist teams and how systematically tracking outcome measurement influences their culture and communication dynamics compared to teams who share the same specialty, but do not systematically record outcomes.

2.1 Inflammatory Bowel Disease Characterization and Burden

Inflammatory Bowel Disease (IBD) is an autoimmune disorder characterized by waxing and waning inflammation of the gastrointestinal tract that leads to debilitating pain and frequent discomfort, severely diminishing patients' quality of life and in some cases increasing their risk for colorectal cancer. IBD is composed of two sister diseases, Ulcerative Colitis (UC) and Crohn's Disease (CD), both characterized by inflammation of the bowel. Disease presence can be indicated by anemia, malnutrition, and decreased bone density [24] and can include symptoms such as abdominal pain, diarrhea, incontinence, dizziness, gastrointestinal bleeding, and weight loss. Effects of these indicators and symptoms often pose serious health risks when left untreated or treated improperly. Estimates are that IBD affects 439 per 100,000 adults [25] in the United States alone, 400 per 100,000 in the UK [26], and 396 in 100,000 worldwide [27].

2.2 Current Treatments for IBD

Current treatment of IBD targets the inflammation that characterizes the disease and measures progress through mucosal healing and the presence of immune components like neutrophils [28]. Ongoing studies are being done to find possible patterns in lifestyle, eating

habits, and genetic factors that contribute to the disease. As patients with active IBD symptoms experience greater levels of distress, feelings of a lack of sense of self-control, and impact on their psychological health [29] [30], it is important to establish the effectiveness of medical therapies that can heal active disease, prevent relapse, and improve patients' quality of life [31]. The therapeutic target is based more on objective parameters such as endoscopic healing and inflammatory markers rather than clinical remission. A 2011 systematic review assessed the most common IBD treatments [32]:

(a) Oral 5-ASA drugs (e.g., sulfasalazine, mesalamine)

(b) Oral traditional corticosteroids (e.g., prednisone or prednisolone)

(c) Oral budesonide

(d) Immunosuppressive therapy (e.g., azathioprine, 6-mercaptopurine (6-MP), methotrexate)

(e) Biological therapies (e.g., infliximab, adalimumab, etanercept, certolizumab)

(f) Antibiotic therapy (e.g., antimycobacterial drugs, metronidazole)

and their effectiveness in inducing remission and preventing relapse in UC and CD. While hospitalization was initially the greatest cost driver in IBD, the introduction of newer expensive biologic medications ("biologics") has now made medication the greatest cost driver [33]. The study also reported that while the surgical treatment of CD is often followed by recurrence and requires re-initiation of treatment[1] [34], surgery for UC is often considered curative, as current therapies for ulcerative colitis are only modestly effective [35] [36], and up to 45% of patients eventually have total surgical removal of their colon [37]. This is a difficult and irreversible decision for young patients to make, especially for young females who can have a three-fold increase in infertility because of the scarring of the pelvic organs after total colectomy [38]. Such

risk makes evaluating all symptoms perceived by patients important in assessing disease activity and determining the efficacy of treatment. This risk also makes establishing guidelines for effective care equally important. In 2010 and 2009, the American College of Gastroenterology and the American Journal of Gastroenterology, respectively, published guidelines on the management of both UC [39] and CD [40] that direct the clinical diagnosis and treatment [31].

Although there was an increase in the number of guidelines in the early 2000s [41], uptake and adoption of guidelines has continued to be hindered by a number of factors including: lack of transparency, lack of a uniform evidence that informs the guideline, and lack of trust in recommendations, as recognized by a report from the Institute of Medicine that defined standards for the development of high-quality guidelines [42]. Additional issues with lack of standardized phenotyping, large enough cohort sizes, and detailed biospecimen repositories, despite advances in understanding IBD's biology, have yet to be organized and implemented in a way that ensures patient health and the structured advancement of IBD care through targeted treatment options [43]. Although agreement on diagnostic decision-making between community care providers and IBD experts exists, the two groups significantly disagree on key management decisions [44]. Patients with IBD often do not receive optimal medical therapy, including suboptimal dosing of 5-ASA and immunomodulatory medications, prolonged use of corticosteroids, ineffective use of steroid-sparing agents, inadequate calcium and vitamin D supplementation, and inadequate screening for colorectal cancer [45]. Approximately one-third of patients have been reported to have poor adherence to prescribed biologic therapy. These patients cited forgetfulness, perceived recovery of symptoms, missed gastroenterologist appointments, difficulties with physician access, noncommercial insurance, and costs as some of the reasons for nonadherence [46]. This often happens because of lack of follow-up due to perceived symptomatic remission and leads to

approximately one third of nonadherent patients or patients without follow-up to experience relapse after discontinuing therapy [47] [48] [49] [50]. Among the top reasons necessitating value-based care achieved through outcome measurement for care delivery improvement are variation in care, insufficient prevention of disease progression, and the ethnic disparities that exist in care across the disease burden [51].

2.2a Variation in Treatment and Process Outcomes

A wide range of treatment and management protocols has introduced the possibility of significant variation in practice and outcomes [52] [53] [54] [55] across the board and in IBD specifically. As independent research has led to advancement in scientific knowledge of specific treatments, the need for connecting and integrating this information increases. Investigators from seven major IBD centers formed the Sinai Helmsley Alliance for Research Excellence (SHARE) in 2010 to integrate the information from basic science, epidemiology and information sciences to advance research across the centers by examining variation between center practices, particularly changes in treatment paradigms. As therapeutic options for IBD management expand, treatment trends have moved towards the earlier use of biologic therapy and combination treatment [56] [57]. One study on a Dutch population, found that over the past two decades, a reduction in early colectomy rate as treatment for UC was observed, with no further reduction in the most recent era, while the late colectomy rate and hospitalization rate remained unchanged over time [58]. Other studies show that such rates vary by referring physician, hospital, state, and country, in which rates of treatment by disease may not be tracked.

Spiegel and colleagues showed that a wide variation in everyday management of UC exists between community and expert gastroenterologists when presented with clinical examples

[44] from the United States. Similarly, significant variations in CD management were seen between community and expert gastroenterologists when provided with sample case vignettes, especially with regards to the use of 5-aminosalicylate (5-ASA) medications [59]. In one of the first studies to describe variation in adult IBD care by GI practice setting, significant variations in care patterns and quality measures were found to exist for CD across GI provider types, without similar variation in UC care [46]. Other studies from the United States, Canada, Europe, and Australia have identified similar gaps in care or in provider knowledge, suggesting that these deficiencies are widespread and not confined to a specific geographic region [60] [61] [62] [63]. Generally, variation in treatment occurs when there is uncertainty about best practice, and the continued variation suggests that there is significant potential for standardization across referral and community practices [42]. These studies demonstrate that the use of surgery varies widely and that there is variation in what is currently considered appropriate [64] [65].

Within IBD treatment, there is no central database that shares this information, and the community is dependent upon intermittent publications of small regions or clinical settings that have tracked this information. The geographic, longitudinal, and public information that has been tracked in the US, however, does not track treatment by disease or with indication of results. According to the Dartmouth Health Care Atlas, data output for the number of inpatient colectomies across counties shows that only 8 out of 67 counties in Alaska had reported their instances of inpatient colectomies per 1,000 Medicare enrollees for at least one year between the years 2003 and 2007 [66]. In Arkansas there was no available recorded data for a single one of its 27 counties between the years 2003 and 2007. This sort of discrepancy between county and state information tracking occurred throughout all fifty states. These unexpected inconsistencies demonstrate variation in data tracking and collection, that there is no central database with

enforced reporting, and that variation exists among the rate of colectomies across the United States. These rates, however, do not demonstrate disease-related information that could help explain why the rates occurred and how they might be improved or compared. Furthermore, it is very difficult to even know if variation does exist without any information. Groups such as the Crohn's and Colitis Foundation [67] and the European Crohn's and Colitis Organization increasingly recognize the importance of shifting these metrics towards more patient centered ones [68]. Recording additional information, even as simple as disease specificity of treatment and treatment outcome could transform the data collected by Medicare into meaningful patterns that could indicate treatment trends and their efficacy.

2.2b Insufficient Prevention of Disease Progression

In regard to IBD management, lack of structured guidelines based on integrated research hinders the prevention of disease progression. Furthermore, even with set and implemented guidelines and reduced variation in care, process compliance does not guarantee outcomes and outcomes measurement is a key component in prevention of disease progression. One study showed it takes an average of 17 years before knowledge gained from randomized, controlled trials was incorporated into clinical practice [69]. Another study reported that an estimated 11% of patients receive care that is not recommended by practice guidelines and is potentially harmful [70] and that only about half (55%) of adult outpatients receive recommended care, regardless of whether the medical setting is chronic, acute, or preventative [71] [72], or whether care involves screening, diagnosis, treatment, or follow-up [73]. Outcome measurement is a way of collating this data in real time so that disease and treatment patterns are recognizable in a timely manner. This facet is unique even from the patterns that are recognizable through retroactive review of

research, as these patterns only depict past treatment decisions and may or may not reflect current treatment options and why the change in preferred treatment occurred. While this information may be useful in explaining treatment progression, it is not entirely helpful for preventing disease progression and understanding how past *and current* treatments might affect patients' disease. Moreover, information offered by retroactive review can only be applied on a population basis and does not provide enough detail to inform appropriate treatment decisions on a patient basis, considering her or his specific case and medical history. Outcome measurement is imperative in addressing this factor particularly because its real-time review makes guidelines adaptable to recognize what is currently effective for a patient and to change what is not effective based on the patterns of recently past treatment.

2.2c Ethnic Disparities in Care

Ethnic disparities in care are a third factor that necessitate VBHC. This issue is prevalent across the disease burden, and even while it is understudied in the case of IBD, it is still present, and may have a more significant presence than currently recognized. Consistent with the geographical data collected by the Dartmouth Health Care Atlas, one study found colectomy rate variation among hospitalized patients with UC varied significantly by race and geographic location [74]. Race and ethnicity are recognized as leading factors in health disparities and in variation across the disease burden [75]. Racial and ethnic health disparities' part in IBD makes VBHC and outcome measurement all the more pressing.

2.2d IBD Care Improvement

The continued presence of variation in care, insufficient prevention of disease progression, and racial disparities necessitate VBHC for all diseases, including IBD. With this in mind, current IBD care improvement is made up of the efforts of dedicated teams whose members work to improve the lives of IBD patients and address the three factors mentioned above. At the Western General Hospital in Scotland, Dr. Charlie Lees runs two clinical studies designed to help clinicians learn how environmental factors, particularly diet, genetics and gut microbiota play a role in IBD. The GEM study is recruiting 5000 young, healthy, first-degree relatives of patients with Crohn's disease in order to perform a baseline assessment and then follow subjects for upwards of 3 years to explore the differences in those who remain well versus those who develop Crohn's disease. The PREdiCCt study is recruiting 1500 patients with IBD in clinical remission and performing baseline phenotyping, nutrition and environmental survey and sampling of blood, saliva and stool. Patients will then be followed via a web portal to provide monthly assessments over 2 years to assess for disease flare. Dietary analysis, whole genome sequencing and full metagenomics of the gut microbiota from baseline samples will then be analyzed in patients who flare and compared with those that stay in remission throughout. Both of these projects work to alleviate variation in care by informing guidelines and biomarkers pertinent to patient outcomes that support evidence-based medicine and work towards learning how to increase the prevention of disease progression.

In the United States, Improve Care Now (ICN), the American Gastroenterology Association (AGA), and the Crohn's and Colitis Foundation (CCF) have begun developing a quality of care process in IBD. The ICN Consortium is the first group to design an outcome registry based on improving IBD care by creating long lasting multicenter collaboratives, sharing performance and

patient registry data. ICN participants have documented a rise in remission rates from 55% to 75% over the past few years [76]. These initiatives direct IBD care toward VBHC, and work to address variation of care and increase the prevention of disease progression.

2.3 Outcome Measurement Applied

Even with the recognized necessity of VBHC in IBD, variability of documentation, and patient nonadherence [19] [50] [77] hinder this goal. This is largely because the measurements that are currently being recorded, particularly quality metrics, do not fully account for factors such as patients' behavioral health needs and hospital readmissions. Additionally, outcome measurements that are recorded are often not standardized and are difficult to translate between different teams and systems. With standardized outcome and process metric measurement, these efforts could coordinate to deliver optimal care for IBD patients by forming an understanding of the causes of these barriers and effective solutions for them. This is because outcome measurement efforts work to understand which results are most important to patients and integrate their consideration into commonly referenced guidelines for daily clinical practice. In addressing the barrier of patient nonadherence through outcome measurement, one chronic care model in 2008 used nurse case managers to make follow-up phone calls and monitor standardized protocols for blood testing, resulting in a decrease in IBD- related hospitalizations [78] . This improvement was made through the careful management of data and continuous optimization of the care delivery system. Outcome measurement refines and codifies clinical practice, developing organization and continuity of independent clinical recommendations and a systematic understanding of research. Creation and implementation of evidence-based standards

of care reduces variation and improves patient outcomes. This includes setting goals and repeated measurement of processes in order to identify how standardizing care impacts outcomes [42].

However, not all outcomes are equally important, and neither are the guidelines that produce them. Tools like GRADE exist to help physicians understand which outcomes are critical for physician and patient decision making [40]. While many disease activity indices exist for UC, none have been developed with formal patient input. There is no consensus excellence standard for the evaluation of disease activity in UC, as illustrated in by the following variation in indices, which include: Truelove and Witt's classification of mild, moderate, and severe disease; the St Mark's Index, which empirically added endoscopy in 1978; simplified versions of the St Mark's Index, including the Ulcerative Colitis Disease Activity Index and the Mayo Score; and noninvasive versions, including the Seo Index and the Simple Clinical Colitis Activity Index [79] [80] [81] [82] [83] [84]. The diversity of indices suggests that none of these has proven satisfactory. Patients reported symptoms such as cramping, stool frequency, stool blood, stool consistency, correlation between disease activity and endoscopic findings as being important to them and are also symptoms listed in indices. However, one study showed symptoms important for patients that are not yet listed in indices include: stool mucus (which seems to be a prominent warning sign of worsening symptoms), the ability to differentiate gas from liquid or solid in the rectum when urgency occurs, rapid bowel movements after eating, as well as anxiety and control over activities, and feeling that certain foods could trigger their flares [85].

Outcome measurement development has worked to undo the assumptions that the symptoms and biomarkers measured in disease activity indices for IBD reflect those symptoms that patients find useful in evaluating the severity of a disease flare. One study found that patients in its

sample confirmed 15 symptoms but not 11 other symptoms found in common ulcerative colitis activity indices and identified an additional 14 symptoms not included in commonly used ulcerative colitis activity indices, which they believed to be important in evaluating the onset or severity of an ulcerative colitis flare [84]. This shows that current indices capture only a portion of the clinical symptoms that are important to patients in an ulcerative colitis flare and may neither accurately measure nor fully reflect patients' experience of ulcerative colitis. These findings present an opportunity to develop better patient-centered measures of ulcerative colitis.

CHAPTER 3 - DATA AND ANALYSIS

3.1 Presentation of Small Interview Sample Set

As outcome measurement encourages communication between practitioner and patient, it is likely that it also facilitates and shapes the communication and culture of the care delivery team. Through a small and highly selected sample set, this paper explores the reciprocity between patient-centeredness through outcome measurement, team communication, and work satisfaction. It is anticipated that outcome measurement does in fact play a large role in shaping team culture and dynamics, independent of structure, in a way that is not only beneficial for the patient but also the care delivery team, and that teams who do not participate in systematic outcome measurement may experience less work satisfaction and have a less patient-centered approach to treatment. The following sections contain interviews with international teams who do and do not measure outcomes. Both teams who do and do not measure guide their practices by varying guidelines of recommended practice, sometimes offered through meta-analysis reviews and in other cases single publications or professional experience.

3.1 a An American- Based GI Practice Without Systematic Outcome

Dr. Sumona Saha is an assistant professor of medicine at the University of Wisconsin School of Medicine and Public Health. She is the first physician in the country to complete a training program in gastroenterology with a specific focus on women's health. Her clinical interests are in Inflammatory Bowel Disease and GI disorders in pregnancy. Dr. Saha is funded by the NIH as a scholar with the Center for Women's Health Research at the University of Wisconsin to conduct interdisciplinary research on women with Inflammatory Bowel Disease.

Her clinic treats approximately 1,000 IBD patients per year, 600 of whom have Crohn's disease and 400 of whom have Ulcerative Colitis. She defines her working team as three gastroenterologists specialized in IBD, five gastroenterologists who see IBD patients but are not specialized in the disease, two advanced practice providers who focus on IBD, GI nutritionists, a registered dietician, a health psychologist, seven colorectal surgeons, and a GI pharmacist. Her team largely considers their "success to be the success of their patient in achieving clinical and endoscopic remission, having well controlled symptoms, tolerating medications, addressing mental health and nutritional status, bowel healing, and mucosal healing." She shared that her team communicates through an online portal called patient panel, where physicians refer patients to other physicians. Dr. Saha feels that integration between medical doctors is important for communication and hopes to include a nurse navigator in her team to help determine the patient's status and needs, so that he or she may be directed to the appropriate physician. She noted that in some ways there is some integration within her team as it shares physical space and referrals with colorectal surgeons. She also explained that the Electronic Medical Record (EMR) also helps IBD care teams work with primary care providers (PCP). Within her team, Dr. Saha follows quality metrics outlined by the Crohn's and Colitis Foundation (CCF) that outline tuberculosis testing, bone density checks, flu vaccines, and chromo endoscopy, a dye spray that enhances polyp visualization during colonoscopy. The outcomes that Dr. Saha's team currently tracks are vaccination rates, DEXA scan rates, which indicate bone density, and hospitalization rates. She feels that there are issues that would prevent effective outcome measurement, particularly that there are "super complex patients, and it would not be good to publish the results" because they would potentially look bad and not reflect the physicians' hard work and professional training. Another factor that she considers a barrier to outcome measurement is the

nature of IBD itself—"it waxes and wanes," she said; and, would not offer consistent opportunities for measurement collection. Additionally, Dr. Saha, shared that there are "lots of phenotypes" involved in IBD and there would need to be a specific outcome for each phenotype rather than a larger general measure set. As far as meetings, Saha and her team gather once a week for their IBD conference, discussing their rotating agenda and clinical issues. She noted that trainees and nurses are welcome, but do not always attend these meetings. "Nurses are at the granular level, and our team would welcome their input in the meetings, but the topics are usually more doctor specific," explained Dr. Saha. She shared that she feels her group is cohesive because its members often recognize each person's contributions, such as publications. She also meets once a week with her collegial team. At large, she expressed she feels "most burdened by the want for additional people, the feeling of fatigue and being over-worked, the need for more health psychology team members, and filling the gaps that will be left by upcoming retirements." She finds that when tension does arise amongst the team, it often occurs around the decision of whether or not to perform surgery versus medical therapy and is often resolved by patient declaration of his or her preference on treatment with the information offered by the gastroenterologist and colorectal surgeon. She also shared that juggling and overscheduling patients is also another point of discussion and frustration sometimes.

3.1b A Scotland-Based GI Practice Without Systematic Outcome Measurement

Dr. Ian Arnott is a gastroenterologist at the Western General Hospital in Edinburgh, Scotland. Dr. James Fulforth is also part of their team as a gastroenterological resident in training. Among their team, Fulforth cites IBD nurse specialists, head nursing staff, infusion specialists, whom collect data but do not have higher IBD qualifications, as well as the pathology

and radiology departments, which have GI specialists, but do not include IBD specialization. They are an IBD center that sees most of the IBD patients regionally from Fife and other nearby areas. The Western General GI ward has the largest IBD patient population in the region. GI resident James Fulforth shared that he feels this population has largely been built by their team's reputation through academic research in the present and past as well as for good treatment and patient reviews that have led to referrals from smaller clinics. According to Fulforth, his team is composed of a clinical fellow, usually an IBD specialist, a research fellow, and a GI resident in training. Within this team, the clinical fellow is often the primary communicator between the patient and nurses. He also shared that his team holds multidisciplinary team meetings with regional gastroenterologists about annually and meets with Edinburgh attendants weekly. Fulforth expressed a general wish from him and his team to have increased support from and collaboration with psychiatrists and IBD nurse specialists. Among their team, Fulforth articulates their definition of success as "more disease focused," and how treatment might minimize the disease. His team measures this success on a patient-by-patient basis, looking at outcomes like hospitalization, progression of disease, and the necessity for surgery. Fulforth shared his team's focus on trying to prevent patient hospitalization through preventative care and patient-centeredness within the clinic. "Patient symptoms do not necessarily indicate how the patient is feeling, or the potential success of a treatment," Fulforth said. As far as outcome measurement, Fulforth felt that integrated care would be an important first step, and that it is likely easier to achieve stabilized health for patients through drug development. In this way, he suggested it would likely be less expensive to offer different prescriptions to patients than to hire the staff needed to track and record these outcomes. He explained that best practice is often informed by research, trying to formalize a network around that research, and monitoring therapeutic

treatment. Dr. Arnott shared that the Western General Hospital GI ward followed standards set out by a government initiative in 2015 [86]. Arnott considers his team to be six gastroenterologists, three being specialized in IBD, three research fellows, one IBD nurse, general nurses, an infusionist, a pharmacist, nutritionist, a rheumatologist, colorectal surgeon and a pathologist. For Arnott, success means resolving patients' symptoms and negative biomarkers.

3.1 c An American- Based GI Practice Without Systematic Outcome Measurement

Dr. Randall Pellish is a gastroenterologist at the Lahey IBD Clinic where he has recently moved from the IBD Clinic at the University of Massachusetts. During our interview, he had not yet moved to the Lahey IBD Clinic, and described his team and experience at the University of Massachusetts. His UMass clinic served approximately 1500 patients per year for IBD and he had annual appointments with approximately 400 of these patients. At the UMass IBD clinic, Dr. Pellish considered his team to be composed of the attending gastroenterologists, two registered nurses (RNs), assistants from the pharmacy who help with prescribing biologics, colorectal surgeons, pathologists, a pediatric gastroenterologist, and a nutritionist specialized in IBD. He added that he would like to see the addition of a nurse practitioner to their team, as this would add an additional clinician to their team who could work highly independently. Within his team at UMass, Pellish explains we "communicate when appropriate for care needs; such as, a patient with a disease flare, deterioration, change in medications, or lab abnormalities." He describes these conversations as a flow that occurs on a daily basis. The UMass IBD clinic physicians use an internally agreed upon protocol that merges some of the criteria outlined by the Crohn's and Colitis Foundation (CCF), the American Gastroenterology Association (ACG), as well as

American College of Gastroenterology (ACG). Dr. Pellish shared enthusiasm for his move to Lahey IBD Clinic because of its more integrated approach to treating IBD. He said that this type of care culture would allow the team to include radiologists, pathologists, gastroenterologists, colorectal surgeons, psychiatrists, and nutritionists, as well as support staff like nurse practitioners, pharmacists, nurses, and psychologists. Additional team members such as psychiatrists, psychologists, and nurse practitioners would allow the IBD team to treat the patient more holistically. He emphasized that "research protocols, original plans to serve the patient, and comprehensive and compassionate care, make you better and keep you better." Dr. Pellish expressed that currently "doctors do not communicate with each other about optimal care, and treatment depending on the gastroenterologist that the patient visits." For his team at UMass, its success is patients' successes in being able to live their daily lives as minimally impacted by their IBD as possible. And in the cases when this success in not achieved, nursing staff alerts the physicians and an assessment of symptoms is made on a patient-by-patient basis. Often the review of metrics includes: markers of inflammation, endoscopic and mucosal healing, anemia, preventing surgery, hospital admission, and whether patients are on steroids. Dr. Pellish highlights that standardized criteria and protocol are important for treatment because physicians are then left uncertain about what to use when, "practicing the art of medicine," and thinks it would be very helpful to have a team of physicians sharing and refining this art and its protocols. With this, Dr. Pellish mentions that outcome measurement at this point is still unachievable because of resources and their allocation at UMass are structured with different priorities, but that it may be more feasible in his new team at Lahey IBD Clinic. On a macro scale, Pellish feels there are so many different settings where patients receive care and information about their disease and that these different settings would make it difficult to collect standardized data. In his

own team, Pellish continues to work towards communication with his whole team to focus on patient treatment at large rather than on a case-by-case basis. To do this, they meet twice a year to address initiatives and protocols that need to be worked on. He also attends an IBD conference once a month to discuss patient care by analyzing case studies of individual patients and works with the resident training program. Additionally, some members of his UMass team are also members of the CCF and have relationships with other teams about how they are doing things. Through this inter group communication, the teams work to develop complex patient care and communicate on case-by-case basis.

3.1 d A Dutch- Based GI Practice With Systematic Outcome Measurement

Dr. Rachel West is a gastroenterologist at the large teaching hospital, Franciscus Gasthuis & Vlietland in Rotterdam, Netherlands. She serves on the national board of the IBD committee of the Dutch association of stomach, gut, and liver physicians (NVMDL) and works with 5 other regional hospitals and the patients' association (CCUVN) to improve the quality of IBD care. The initiative spanning the 5 hospitals works to measure both "clinical outcomes, which measure the doctor, and patient reported outcomes," said West. In this program, the patient fills out questionnaires once a month and the results are recorded on an electronic portal. This information is then manually reviewed by the nurse specialists who summarize the survey and annotate the electronic patient record with any changes from the last survey, such as increased feelings of depression. The annotations are then available to both the patient and physician so that they can discuss them in their next appointment. If the physician and patient decide outside care from a psychological or social worker, this is discussed in the multidisciplinary team meetings. Dr. West is the one of the leaders of her team within the IBD center. Her team is

comprised of 11 gastroenterologists, 3 specialized in IBD care, nurses, IBD nurse specialists, pediatric gastroenterologists, colorectal surgeons, and dieticians. The multidisciplinary team includes pharmacists, psychologists, and social workers. The gastroenterologists and nurses meet once a week and the multidisciplinary team meets every other week to discuss the annotation of patient charts. The purpose of these meetings is to try to provide uniform care for patients, while recognizing that "every patient is different," and has different priorities.

West explained that putting together her IBD team has been a process that started with all of the members agreeing to be an IBD care team and then deciding how they were going to track outcomes. She explained that their goal when treating a patient is to take the patient's priorities into consideration, asking themselves "can patients do everything he or she wants?" West stated this was her definition of success. She shared that beginning to measure outcomes was the most difficult stage of the process and expressed that "there was more work when we introduced the outcome measurement." West continued, "but, when we got [the program] going, the patients' disease was in control, and we began getting respect from our patients, our whole team felt motivated. It shows that your hard work is actually going somewhere."

She shared that, as the leader, it was her interest and enthusiasm for outcome measurement that began the program and lead her to include ICHOM criteria in the database, but it is the enthusiasm of IBD nurses that fuels the continuation of the project and ensures that the data is recorded and reviewed. West feels that her team's dedication to outcome measurement shows "more attention to the lives of patients with IBD." She shared that she is looking forward to the growth of outcome measurement, particularly through ICHOM, that will allow her and her team to continue learning on a national and international level. Currently, West says there is not a lot of data published on outcome measurement in IBD, and that initial motivation for the

project required her enthusiasm to motivate the others, expressing that the success of the project is what has really converted them to believing in outcome measurement. With publications of their outcome measures on their way, West shares that her team continues to discuss the best way to treat individual patients, considering his or her priorities, and what their team should focus on next, whether it be "quality of care or focusing on outcomes, or other aspects of quality of care."

3.1 e A Dutch- Based GI Practice With Systematic Outcome Measurement

Dr. Marieke Pierik is a Gastroenterologist at Maastricht University Medical Centre (MAUMC) in the Netherlands and served as an affiliate with the development and implementation of the ICHOM IBD standard set. She is a board member of ICC (Initiative on Crohn's and Colitis) and ECCO (European Crohn's and Colitis foundation). Her scientific research focuses on the course of IBD, markers for IBD disease activity, and the role of food and intestinal bacteria in IBD. In 2017, Dr. Pierik and her team developed an E-health application, called MyIBDcoach, for chronic bowel disease. This tool resulted in a 50% reduction in hospital admissions, and improved medication adherence, as published in the Lancet journal [87].In addition to this system, Dr. Pierik and her team created a specific form called SNOW to track the classical outcome data their hospital had been tracking for nearly 15-20 years and transitioned to electronic data records so that the information could be collated and accessed more easily. These two tools combined patient reported outcomes with process outcomes to help Pierik's team recognize patterns in treatment and develop a highly effective protocol that extended beyond just the classical process measures set out by the Dutch national and European gastroenterological standards. The survey information collected by the E-health app worked so

well, it drew national attention from pharmaceutical companies interested in collaborating with a system that promoted patient medication adherence.

The new system works because it includes additional modifiers outside of patient reported outcomes including: age, social network, psychiatric comorbidities, smoking and malnutrition, recognizing a more holistic view of factors that affect chronic disease. Program success is furthered by the data allowing the hospital to make a network of care pods, a group including a physiotherapist, dieticians and psychologists. These health care professionals help patients recovering from IBD debilitation to reintegrate into the work force. From this enhanced information, Pierik and her team used their web-based tools, modifier measurement, and patient-based outcomes to develop a structure for the entire cycle of care.

The web-based system sends out a survey to patients that flags when a patient reports certain symptoms that require immediate attention, for example: three or more stools a day with blood. This flag then sends a message to both the medical team and patient prompting to schedule an appointment. All other patients who do not receive a red flag, are prompted to schedule an appointment once a year. Because of its success in decreasing hospitalization, the E-health system has been implemented in twelve other Dutch hospitals. Pierik says that the system will begin to include additional metrics that have subsequently added to the International Consortium of Health Outcome Measure set following initial implementation. She expressed that this "app is a very important way to reduce biologics because you can track outcomes from a far," as it allows medical teams to address patient's health concerns before they escalate to an emergency level and require such medications and treatment.

In our interview, Dr. Pierik emphasized the importance of all team members and stated, "nurses are better than doctors at recording and adhering protocol information," and our team

work is a thorough integration between the efforts of physicians and nurses. Dr. Pierik describes her medical team as nurse practitioners specialized in IBD, a dietician, gastroenterologists and colorectal surgeons, who all work within a network of physiotherapists and psychologists. She hopes to expand her team members to include her specialized team with general practitioners (GPs). In order to maintain such a program and its results, Pierik's team at MAUMC hosts a logistical meeting between the gastroenterologists and nurses once a week, to discuss topics such as ongoing trials as well as social topics like how they spent their vacations. In addition, the team also holds weekly multi-disciplinary IBD team meetings that include the dieticians, colorectal surgeons, physiotherapists, and psychotherapists with the core group of gastroenterologists and nurses. Pierik emphasizes that scheduling dialogue is critical for communication and explained that gastroenterologists meet with nurses thirty minutes a day for a nurse to talk with the physician about flagged surveys and any questions on how to proceed. As far as connecting with outside groups, the UMAC team meets with the twelve other Dutch teams every 2-3 months during board meetings with the foundation in order to structure and align the multi-center IBD projects with Dr. Pierik's project.

Even with a singular mission, Dr. Pierik shared that there is sometimes disagreement with how important patient perspective is. One new younger team member "thinks our program over-pampers the patients," she said. He feels that patients being able to see their lab results through their E-health portal is unnecessary because they often cannot interpret the results and raise additional questions with the physicians, she explained. For example, in some cases, patients who use immunosuppressants should have themselves checked by GP, but they instead contact the IBD center because the center is the group in charge of the E-health app. She finds that these differences in opinion, however, have served as constructive conversation tools in meetings and

help serve as reminders about the importance of measuring outcomes and expanding communication of ideas within the team. Within the structure of the program, Pierik is still working on patient and provider education and how to improve care pods and the extension of the program through the care cycle. These efforts are formally discussed annually at a physical meeting on care pod improvement and all of the health care professionals involved.

The team often shares a sense of collective mission, a larger purpose that unites and focuses their professional efforts. Pierik says:

> "This project changed me to the good way again, seeing what matters to patients is humbling. It can make you cynical to work in the hospital over and over after ten years— if I worked in a company I could have been a major executive— but in medicine physicians are still in the same job."

Overall, Pierik feels her UMAC team is making big steps in promoting measuring outcomes. She noticed that many groups who newly start measuring outcomes usually begin with measures that are too scientific, like biomarkers that are not easily recorded or that do not necessarily indicate patient wellness. She says these measurements prevent outcome measurement implementation in hospitals, as they cannot be used generally and do not factor in the comorbidities that many patients with chronic disease have. For example, "endoscopic remission doesn't mean the patients feel well; and, social support, and eating health is so important," Pierik said.

2.4f An American- Based GI Practice With Systematic Outcome Measurement

Dr. Corey Siegel is the Director of the Inflammatory Bowel Disease (IBD) Center at the Dartmouth Hitchcock Medical Center in New Hampshire and Co- Chair of IBD Qorus, an outcome measurement initiative established through the CCF. Dr. Siegel researches risk/benefit

tradeoffs in IBD, developing models to predict outcomes in Crohn's disease, creating tools to facilitate shared decision making, and improving the quality of care delivered to patients with IBD. Dr. Siegel is the founder of the BRIDGe group, an international research collaborative of IBD investigators and sat on the international committee that developed the ICHOM IBD standard set. He also serves on the editorial board for *Clinical Gastroenterology and Hepatology* and *Alimentary Pharmacology & Therapeutics*.

A leader in outcome measurement including patient reported outcomes, Siegel's Qorus is a program that includes an online survey for patients to fill out before they arrive at the doctor's appointment. This allows the physician and patient to go through the survey responses together. The program began in an effort to address variations in care delivery and improve its quality for patients with IBD. The committee first identified key treatment processes and patient outcomes that could be measured to form a baseline against which a patient's progress can be tracked over time. The Qorus development team intends the online platform to enable collection of this data and establish knowledge communication through patient-provider interactions at the point of care. As Dr. Siegel stresses in his statement on the Crohn's and Colitis Foundation site:

> "As healthcare providers, we can focus too narrowly on the disease, and lose sight of the individual patient we're trying to help. We must listen and be guided by what's important to each patient, to preserve or improve his or her quality of life. This collaboration between doctor and patient, or treatment as co-production, is the cornerstone of Qorus."

The developers of IBD Qorus aim to establish a collaborative, ongoing care network for IBD patients that enables healthcare providers to communicate ideas and report quality metrics using a common platform. This will facilitate results to be compared over time and across a variety of care settings such as university and community-based academic medical centers, small faculty

practices, large community private practices, among others. Siegel, the Qorus team, and participating providers will all receive coached performance feedback, so that they may learn from one another to improve their levels of IBD care. The IBD Qorus concept basis comes from the "learning health system" and incorporation of quality improvement methodology used by the Dartmouth Institute for Health Policy and Clinical Practices (TDI). This system of symptom tracking, self-management, and shared decision making between patient and provider will measure and improve quality of life for adult patients as well as facilitate their communication during and between visits.

When fully developed, IBD Qorus' technology platform will enable data analysis and patient population management and will allow participants to look at their own data on a continuous basis. Patient-reported outcomes, concerns, and disease activity assessments will be integrated into a patient-centered dashboard to help patients and providers communicate about current health status and effective procedure. Data from each participating site will be reviewed and analyzed at a macro level and will be organized and shared to spread ideas and help in the assessment of best practices. The large data management platform capability of IBD Qorus will enable researchers to integrate, compare, and analyze quality of care data with the scientific and patient-reported data from Plexus' research- and patient-facing aspects, spurring novel research studies to rapidly advance the identification of better treatments for IBD.

Another step in this process is the development of care pathways. Pathways define the sequence as a patient moves from screening to evaluation to intervention to follow-up. IBD physicians and experts in clinical care pathway development, as well as related experts, have come together to articulate the best process for care modules designed to streamline and standardize an approach to specific areas within IBD management. Nutrition and anemia are two

care pathways currently under development, with other topics to follow. Care pathways will be iteratively tested at IBD Qorus sites, with data gathered through the Qorus platform that will yield new insights and information to improve IBD care across the Qorus network and beyond. The data and findings generated from IBD Qorus will contribute to the development of healthcare policies and strategies impacting IBD care worldwide. The result may yield greater efficiencies and a reduction of costs in healthcare management. For example, the initial health learning system from TDI and the IHI not only improves patients' experience in receiving urgent care but will also help them avoid expensive and potentially harmful emergency treatment in the first place.

Dr. Siegel considers his core team to be high quality, with three members including himself, a gastroenterologist, his nurse coordinator, and nurse. Between the three of them, they have a weekly team meeting to discuss high-risk patients. Siegel considers his extended team to be the four other GI providers and one nurse practitioner at the Dartmouth Hitchcock IBD Center. Dr. Siegel says his team largely tracks success by process measures such as how often meetings occur within the team, the proportion of time that high risk patients get in to see them (90 days) and the outcome measures retrieved from Qorus data every month that include how frequently patients believe they need urgent care. As far as procedural outlines, Dr. Siegel follows the protocol set out by the Crohn's and Colitis Foundation. However, he notes that among teams participating in Qorus, the process measures and protocols that are followed vary by site. Siegel says that outcome measurement has not yet become common in medical practice in the United States because it is not embedded in culture and there is low motivation to self-monitor. He notes outside efforts to promote medical excellence including threats from the "Center for Medicaid and Medicare Services to cutback reimbursement if [medical teams] do not

do quality work," mentioning that recording outcomes does require additional time and effort. Emphasizing communication, Siegel explained that discussions begin within his core team to see what protocols work for both patients and providers to achieve the targets set by the larger Qorus mission. This protocol is then shared throughout Siegel's extended team at Dartmouth Hitchcock and the thirty other teams participating in Qorus about once every month with larger meetings every year. "Start with your champions, get it right, find the best way to register patients, master it yourself first, and then spread the mastery through the program, share the data that has been collected among everyone and show that they are actually making a difference," he stated. Siegel says achieving medical excellence through outcome measurement is an initiative fueled by believers. He expressed a sentiment of motivation shared by the participating teams in Qorus. "We are part of something different and bigger," he said, "forty people were on the call this Thursday at 8pm at night; and that doesn't happen through a feeling of obligation, but a sense of longevity in what we are doing." When teams feel so part of something, "time is our barrier" rather than one another, he expressed.

3.2 Interview Analysis

This small sample of teams reveals a dynamic connection between measuring outcomes, team structure, reducing physician burnout and good results for patients. Outcome measurement shapes team culture, and both are integral to good results for patients and decreasing physician burnout. All six of the clinicians in this sample indicated positive patient results as a marker for their own success. However, groups who measured outcomes seemed to have a stronger sense of positive team culture, team communication, patient-centeredness, and work satisfaction. Statements from the groups who measure patient outcomes expressed a sense of accomplishment

and satisfaction because outcome measurement offered them a concrete marker for success. Teams who did not systematically record outcomes expressed varying degrees of work satisfaction, patient-centeredness, and communication frequency and focus. In this respect, not systematically recording outcomes did not guarantee any specific team qualities, whereas systematic outcome measurement did. Expression of team success, communication, culture, motivation and sense of purpose, and outcomes are consistent among teams who systematically measure outcomes and can.

3.2 a Defining Success

In the interviews here, the three teams who measured outcomes used words like "exciting," "purpose," "motivated" (West 29), "tangible change" (Siege 30l) and "the good way" (Pierik 33) to describe their attitudes towards their work. This contrasts sharply with another physician's words like "burdened," "fatigue," "over-worked" (Saha 24). The teams who measured outcomes felt a greater sense of purpose and positivity surrounding their work compared to the one physician who reported a rather negative disposition towards her work (Saha 24), and the other two teams who were neutral towards their work (Pellish 27, Arnott 26, Fulforth 25). All three teams who do not measure outcomes explicitly stated their definition of success to be the health success of their patients. Two teams even gauge patients' success through outcomes like "hospitalization rate, progression of disease, and necessity for surgery" (Fulforth 25) as well as "patients being able to live their daily lives as minimally impacted by their IBD as possible" (Pellish 27). These outcomes are measures agreed upon by consortiums like ICHOM and IBD Qorus. The only difference is that these two teams do not track the outcomes they use and in turn cannot measure the larger success that they presently feel or hope

for. In the third team, "biomarkers such as endoscopic remission, having well controlled symptoms, tolerating medications, addressing mental health and nutritional status, bowel healing, and mucosal healing," were the indicators of doctor and patient success (Saha 23). However, as Dr. Fulforth pointed out, "biomarkers do not necessarily indicate how the patient is feeling, or the potential success of a treatment" (25). This means that a focus on measures other than outcomes may not result in patient well-being.

3.2 b Communication

While team structure was similar amongst the five groups, team communication and culture varied by teams who do and do not measure outcomes. In teams that measure outcomes, team communication was structured with set meetings and dedicated time to talking specifically about criteria that need to be addressed to reach their goals. Most importantly, however, these criteria are patient results that indicate a patient's progress towards her or his health goals. Such a practice directs team communication toward success for patients, and subsequently the team's success. The Dutch team that measures outcomes through their E-health application, schedules meetings between their gastroenterologists and nurses for thirty minutes a day so that they may discuss patients whose symptoms have raised a flag in the system. This demonstrates how outcome measurement focuses communication around what really matters to the patient rather than biomarkers alone that do not always indicate how the patient is feeling. Additionally, the methodical structure of outcome measurement and review of results facilitates structured communication times focused around these outcomes. It is also important that these teams set times committed to these discussions (Pierik 30), as priorities without committed follow through fall often fall to the wayside. Such is also true for outcome measurement and achieving patients'

health goals. This is different from the second group of teams that do not measure outcomes, as they described their communication as a "flow" of daily exchanges that occur when necessary (Pellish 26). While their communication is regular, it should be noted that these teams may not have established a structured set of criteria for what concerns warrant conversation, and possibly depend upon the intuition of nurses and physicians. Medical training prepares individuals to make these informed intuitive decisions and progress could not be made without the brain power of the members of medical teams; but, without a minimum set of standards to review, a basis for the growth of this intuition cannot be established.

3.2 c Team Structure and Culture

Research shows nurses, behavioral health specialists, and dietitians have started to play an important role in improving care in IBD patients [88], and that the culture of a team shapes their interactions and positively influences its efficacy and patient outcomes. Without coordination and clearly defined roles among team members, burnout threatens the engagement of team members and quality of patient care. Studies show that team culture and team structure were independently associated with staff exhaustion [89], where culture was a predictor of exhaustion and structure helped only when paired with culture and not on its own. The teams who do not measure outcomes seemed to focus more on changing their practice by adjusting their structure through introducing more/different team members, rather than changing team culture. This group, across all three teams, mentioned a want for additional nurses as part of their team. Such an addition would provide more support from team members who could work highly independently (Pellish 26). It may be the case, however, that increased number of team members does not increase the efficacy of the team, largely because such an addition does not change

fundamental team culture. Communication and its resulting culture are often visible through the expression of team structure. The same team that described feelings of "fatigue," and "being over-worked," explained that the nurses on her team are at the granular level and do not attend team meetings, because the meetings are often "more doctor specific" (Saha 24). This is a large contrast from the team who describes its nurses as "integral to following protocol," and in attendance at all meetings and whose leader shared feelings of satisfaction and avidity for her work in helping patients (Pierik 31). This same team also communicates about disagreements regarding disagreements about how much detailed information, such as lab results, patients really need to have. These conversations were described as learning experiences and opportunities for other team members to raise any concerns that they have as well. These group dynamics can foster an environment in which front-line staff want and feel comfortable to share their insights on how to better improve outcomes and clinicians feel encouraged to make direct comparisons with one another, to review their own performance. As presented by Derek Feeley at the IHI International Forum in Glasgow [90], teams who focus on patient care and outcomes have a higher level of involvement in their work and a 58% decrease in patient safety incidents. Safety is important, and the culture of team dynamics can help achieve this goal.

Dr. Siegel explained that each of the thirty teams participating in Qorus has a different structure of gastroenterologists, nurses, and other team members, but that the uniting factor between all of them was the outcomes they measured. This common comparison between differently structured teams with varying resources is possible because outcome measures focus on patient wellness. Understandably, it can be anticipated that there might be varying outcomes based on the structure of and resources of the team. Knowing that effectiveness is associated with team culture and structure, it makes sense that teams of varying structures would all be able

to achieve excellence. This is an indicator of outcome measurement helping to develop a culture of communication, learning, and teamwork, leading to a more positive outlook on their practice. As outcome measurement is a means of communication between patient, physician, and team, it makes sense that outcome measurement would positively influence the culture of a team. One study shows that a team culture of communication and that cultural and structural changes can improve team effectiveness [87]. Culture, structure, and communication are also influenced by members of the team and varying professional perspectives. Integrated care that includes psychiatry, nutrition, and pharmacy services can lead to better patient outcomes because of increased communication between the disciplines that treat the individual.

3.2 d Team Motivation and Sense of Purpose

Both Pierik and Siegel show better results for their patients through these outcome measurement efforts and initiatives, and they may also have positive implications for their medical teams. As Dr. Siegel puts it "measuring outcomes gives groups a purpose, and is exciting to be involved in, particularly when there is tangible change." Measuring outcomes is a structured way of communicating between physician and patient, encouraging a more meaningful and effective doctor-patient relationship. This communication then extends between physicians and their team as they observe data and use it as a learning tool. Focusing on measuring outcomes that account for patient well-being frame medical teams' focus around understanding the disease as a part of a person's life and the outside factors that can contribute to the expression of their disease. The resulting differences in team motivation and sense of purpose, patient and team success, and communication within the team seen in this small sample of teams interviewed here are a vignette of a growing body of research. Studies show that team

work, communication, culture and their quality are important on a large scale from specific techniques of gastroenterological endoscopy to team effectiveness on whole [91].

Leadership and communication are important for overall effectiveness beginning on the level of single techniques, such as endoscopy. One study cites the endoscopy team and its leaders as components for a highly effective endoscopy service with critical team characteristics being: shared purpose, good understanding of individual roles, clarity in the decision-making process, regular and meaningful communication, problem solving, effective operation, striving for continuous improvement, flexibility and adaptability, individual support and development, and recognition and reward [88]. These technical team traits collect and contribute to effectiveness on a wholistic level. The study also showed that effective teams are similar in leadership, commitment to patients, and clear roles/responsibilities, independent of setting, and that teams that measured outcomes were more likely to have these traits. In whole, this study showed that effective teamwork in health care contributes to a positive organizational culture and improves patient safety and outcomes, indicating communication and coordination among team members can be key to promoting team effectiveness and outcomes. It is important to understand that effectiveness, quality, and value are all cumulative ends that are made up of the individual communication and technical practices that compose them. This means that a team that achieves good outcomes does so through effectively executing and structuring small daily tasks such as conversation, decision making, and forming a knowledge base in a meaningful way that helps the group achieve good results for patients. This is the key function of outcome measurement.

Most importantly the achievement of effectiveness benefits the team as well as the patient, offering an increased sense of motivation, purpose, and work satisfaction. Another study

shows that working in a tight team structure and the perception of close team culture were associated with less clinical exhaustion [87], stating that:

"Clinician burnout and corresponding professional dissatisfaction have been associated with medical errors [92] [93] [94], reduced quality of medical care [95] [96] [97], poor communication with patients [93], longer recovery time following hospitalization [98], poor adherence of patients to care plans [99], lower patient satisfaction [94] [100], and a reluctance to take on new patients insured by Medicaid or Medicare" [101]. Clinician well-being has been proposed as a quality indicator [97] and team-based care could help ameliorate being overwhelmed by the demands of medical care [102] [103]. This is the core paradox of outcome measurement. As discussed in the next section, one of the largest cited inhibitors in this sample-set for why systematic outcome measurement was not taking place was time; yet, the above study and the interviews from this small sample seem to suggest that this feeling of limited time is connected to clinician burnout and that in changing the focus of care to patient-centeredness through outcome measurement, could diminish this sense of fatigue and time limitation. This sample supports that measuring outcomes helps a team to tighten by identifying a purpose of helping patients and achieving better health results.

3.2 e Discussion on Outcome Measurement

With much evidence for the necessity, if not ethical obligation, to measure outcomes for both the benefit of the patient and the care delivery team, many questions and concerns still prevent practitioners from participating in this important initiative. Fortunately, the outcome measurements initiatives already in progress can respond to many of these apprehensions. Among the reasons teams cited for not measuring outcomes were: the specific patients of that

physician were complex and published outcome data would not reflect the hard work and dedication of the physicians; the nature of IBD itself, the disease is characterized by active and latent stages; the existence of too many phenotypes to have a single standard set; drug development being easier and less expensive than hiring the staff needed for outcome measurement; too few financial or staffing resources; different provider settings would not allow for a fair comparison. While it is understandable that developing an established set of guidelines has logistical implications that must be accounted for, it is imperative to recognize outcome measurement as fulfillment of practitioners' professional and ethical responsibility to patients as well as fulfillment of both practitioners' and patients' goal for patients to live their daily lives as unaffected by their disease as possible.

The first point of reticence mentioned in the interviews in this work was that the nature of IBD itself would prevent outcome measurement because the disease is characterized by active and latent stages and there are too many phenotypes to have a single standard set (Saha 24). This point was independently addressed by a different team who measure outcomes and mentioned that "many groups who newly start measuring outcomes usually begin with measures that are too scientific, like biomarkers that are not easily recorded or that do not necessarily indicate patient wellness" (Pierik 33). The team explained that this kind of measurement prevents outcome measurement implementation, as it cannot be used generally and does not account for the comorbidities of many patients with chronic disease. For example, "endoscopic remission doesn't mean the patients feel well; and, social support, and dietary health are so important," Pierik said. In this way, the nature of the disease is not so important as capturing the picture of patient well-being, and that measuring outcomes is really more about the patient than the disease. This is really the heart of outcome-measurement. Currently much of the measurement that takes

place in medicine are process metrics that are sometimes mistakenly referred to as outcomes. Patient-centeredness is core to outcome measurement as it considers what matters most to the patient.

The second pushback to outcome measurement was that drug development is an easier route to achieving results and is less expensive than hiring the staff needed for tracking outcomes. This is the model of medical progress currently practiced. It is an ideological basis that focuses largely on treatment of disease rather than the patient. It is true that drug and technical developments have exponentially improved quality of life and its span over the last 150 years. The average life span in the UK was 38.5 in 1847 and was 81.4 in 2015 [104]. Yet, this approach is as much medicine's current downfall as it was its past success. Present research indicates that overuse of care is the basis for much of the ineffective treatment and medical spending globally and is particularly an issue in the United States [105]. Further research demonstrates that poor use, including overuse, of medical services results from lack of patient-centeredness [106]. It is imperative to understand that overuse does not simply mean wasted resources at no cost to the patient, but that "overuse is likely to cause physical, psychological, and financial harm to the patients," as well as "deflect resources from public health" [100]. Furthermore, it is shown that communication is the most important way to achieve patient-centered care [107] and that this type of care is core to outcome measurement as it helps reinforce practitioner and patient understanding of the health concern and the best way to move forward [101].

As medical practitioners are a community of highly-skilled, dedicated, and compassionate individuals, the third concern that different provider settings would not allow for a fair comparison between outcomes makes sense. From small private practices to large

university IBD centers, it is clear that different groups have difference resources and levels of preparedness to address one set of health concerns over another. Indeed, it is possible that the large university IBD center with concentrated resources and practice with IBD has different results than a small private practice that hosts a skill set and resources primarily dedicated to a different mission. This is the reason for learning collaboratives like Qorus and Improve Care Now. Physicians from small private practices can learn from and with larger organizations to serve patient better. Their fear overlooks the core of outcome measurement as a form of communication as a means for learning in order to achieve medical excellence for the patient. Dr. Corey Siegel independently responded to this common concern in our interview. He explained that many different care settings do not affect the comparability of results because the results are patient outcomes and depend upon the patient's health status and progression. Furthermore, the intention of comparing the outcomes from two such settings would be to learn how each setting might affect patient results, and as patient results are largely connected to team culture rather than structure, these results may be much less dependent upon resources than medical professionals fear. These results could be indication of the potentially most effective care delivery team culture and may provide support for which structures and minimum resources are required for effective care. It is also possible that these results might indicate necessary change like the most effective time to refer an IBD patient to a specialist versus staying with primary care.

In response to Dr. Siegel's statement that patient outcomes are more about patient progress than the physician's resources, many physicians would argue that their patients are unique and particularly complex compared to other physicians' patients and that published outcome data would not reflect the hard work and dedication of the medical team. However,

according to a study from Dr. Brent James, one of the most respected health care quality experts in the US, argues that it is almost never the case that patients attending one practice are sicker or have more complex cases than those of another; moreover, many patients admitted for a specific treatment across hospitals are admitted for the same characteristics [108]. Instead the study demonstrated large variation in care between providers, even if the provider was consistent in treatment. In this way, it may be that clinician perception of severity or complexity of disease is related to the treatment offered and could be improved through standardization of guidelines that minimizes such variation and perception of patient disease severity.

Moreover, there was an expressed association between the necessary data entry for outcome measurement and the perceived burden of electronic health record (EHR) documentation, which has a known contribution to care and documentation variation as well as physician burnout [109]. Outcome measurement platforms have duly addressed this issue by creating procedures and structured communication that are seamlessly integrated into daily clinical practice, as well as electronic means of communicating with patients and having them document their symptoms in real time allowing for comprehensive and cohesive documentation.

Others acknowledge the potential benefits of measuring outcomes but share concerns about the implementation of outcomes and having too few financial, staffing, or time resources. While it is true that some resources are required to measure outcomes, these resource additions do not come from employing more staff members or making large financial investment in new equipment. Most importantly, given the complexity medicine and patient conditions, it is impossible to deliver good care consistently without outcome measurement and makes organizing and obtaining these resources all the more important. Fortunately, there are an increasing number of platforms and initiative to help medical teams measure outcomes, for many

diseases including IBD. Most importantly the largest indicator of effectiveness is culture. Attitude does not require financial resources, but a change in disposition, and an organized focus towards patient outcomes. Dr. Siegel did concede that measuring outcomes does require more effort, and that current medical culture is not structured to reward this additional effort financially. He also mentioned that there are new initiatives to reward quality in medicine through Medicare and Medicaid, but that these are slow moving. Siegel mentioned that the teams who measure outcomes must see their efforts rewarded by the improvement of their patients' health. This does not mean that physicians who do not measure outcomes do not care about their patients, but rather that when physicians do measure outcomes, they can ensure that their efforts are going directly towards the betterment of their patients' health.

3.3 Discussion Application

The group of teams above is a small, highly selected sample of some of IBD teams. One study shows that treatment of IBD has changed throughout time, not because the need or effectiveness of treatment has changed, but because protocols used by physicians have changed [57]. This is contrary to patients' commonly held belief that the treatment recommendations and decisions made by their physicians are evidenced-based. Wide variation in processes and results indicate otherwise. Medical teams use the resources available to them to provide the best care possible, but the most popular resources have not yet included outcome measurement. This is presently changing with the initiatives like ICHOM, and QORUS and Improve Care Now, in the world of IBD.

While some interviewees expressed the barriers they feel prevent large-scale practice of outcome measurement and VBHC efforts are made from perspectives of coordinated care or cost rather than outcome measurement as the initial or crucial step to improving care, Intermountain

Healthcare is an example of how measuring outcomes establishes evidence-based protocols, that increase team communication, improve culture, decreased physician work time, and increase value. Most importantly, efforts to achieve these goals that were made without proper outcome measurement failed, demonstrating that outcome measurement is imperative to improvement, and that improvement cannot be made without outcome measurement. Intermountain Healthcare is an integrated delivery system of 23 hospitals and 160 clinics that provide more than half of all health care delivered in Utah and Idaho. This example makes the same refutations expressed in the section above but is powerful in that it makes these points within a single case.

Shifting focus from provider to process variation showed Intermountain that hospital admissions for a specific treatment had similar characteristics and that declines in variation were associated with large declines in costs, while patient outcomes remained at least as favorable as before. In refining variance measurement, they blended the guidelines into the flow of clinical work through adding checklists and flow sheets rather than a top-down overhaul approach that required practitioners to follow the guideline from memory [110]. Variation for patients with acute respiratory distress decreased from 59% to 6% in four months and patient survival increased from 9.5% to 44% [111]. Physicians' time commitments decreased by about half and the total cost of care decreased by 25% [112]. Any necessary modifications made to the guidelines during clinical practice were recorded and systematically reviewed and adapted. On the two previous occasions of improvement efforts, the data system had not been changed to achieve clinical management because they did not track 30-50% of the data critical to managing processes. This meant that outcomes could not be properly tracked, thus preventing progress of the improvement effort, showing that improvement has a dependent relationship to outcome measurement, and that other improvement efforts must be made in tandem with outcome

measurement. Furthermore, it was found that measurement for selection such as ranking the performance of care providers so that health care consumers can make choices toward high-value care does not produce care improvement, whereas measurement for improvement does and also supports measurement for selection [113] [114] [115]. Moreover, these improvement efforts led the groups to meet monthly with the physicians and nurses who deliver care in their region. This is a similarly structured communication style that was also observed in the interviews in this thesis as well as the Texas Children's case study. These changes lead to being able to see more patients without increasing bed numbers because hospitalization time was decreased. These policy changes were crucial in achieving high-value care, particularly through the management and subsequent organization of care that informed teams at the bedside with patient-centered care and overall population health improvement. Lastly, it is estimated that such measures applied on a notational scale would lower national health care costs by $3.5 billion annually [107].

In IBD treatment, biologics, steroids, and colostomy are treatments that help many patients, but are effective only in some cases, can be harmful in others, and could potentially be more effective when administered at a certain stage in disease progression with a defined set of symptom and general health criteria. Improvement efforts such as ICHOM, QUORUS, and Intermountain Health Care are working to make similar improvements for the care of IBD patients. The key to outcome measurement is the understanding that not all treatment is helpful in a specific situation and it is necessary to discern which treatments and delivery circumstances actually are efficacious. Because of the potential harm treatment carries, the medical community has an ethical obligation to learn which approaches lead to which results. Despite the creation of coordinated care programs for IBD across the world, reported outcomes remain sparse, and the

value of care delivery has remained the same [116]. An evaluation of clinical documentation for 783 IBD patients showed a measures documentation rate ranging from 17-80%, but in fact only 6% of patients had all core measures documented [58].

CHAPTER 4 – FUTURE RESEARCH

4.1 Outcome Measurement within Value-Based Care

Through this small sample, I found a difference between teams who did and did not systematically measure outcomes. Teams who did not measure outcomes expressed hesitation about measuring outcomes and expressed some sentiments that indicated they did not fully know or understand how outcome measurement works. One team expressed that it felt even drug development, one of the most expensive and time-intensive means of treatment in medicine, was more achievable than outcome measurement. This was a sharp contrast from the expressions of teams who did systematically measure outcomes and shared results of reducing cost, lowering harm to patients, and decreasing physician burnout. Outcome measurement sounds revolutionary, ambitious, and idyllic because the impact it has is. However, these grand ends are reached by rather straight-forward, cost-effective means. Teams must start small and start now and have resources available to them through outcome measures pioneers who have already begun to develop the technology and framework needed. Teams can start by measuring under five outcomes that are important to both patients and the team itself, observing their results and watching the difference it makes in their practice and patients' lives. Outcome measurement implementation requires leadership and the value of patient results. Dr. West and Dr. Siegel describe outcome measurement as an effort founded on communication from the initiation of the project throughout its implementation. Siegel describes the initiative as starting with a leader who brings the idea to the team and sparks the group's enthusiasm. The team as a whole must discuss what outcomes are, which ones are important, why it is important to measure them, how it will be applied to the specific practice and disease, and how it will be incorporated into daily clinical practice [117]. Dr. Pierik recalls that not all team members were enthusiastic about the

project from the beginning, but that their questions and concerns became important discussion points for the team as the project continued and grew. As demonstrated by the Intermountain and Texas Childrens' case studies, it is important to determine which outcomes are most important for the disease in focus and to structure team culture around those values. The beginnings of the VBHC initiative have involved much deliberation on which outcomes and process metrics are most important for meaningfully tracking patient improvement and health care change. In the case of IBD, and many other diseases, ICHOM has established a standard set of outcomes with international consensus and gives detailed directions for the implementation process. Through discussion of the effects of outcome measurements on the culture and dynamics of IBD teams, outcome measurement is a key mechanism in shaping VBHC for both the patient and the physician and should be at the heart of all care improvement efforts.

The next stages of VBHC require the recognition of outcome measurement as integral to integrated, compassionate care, staying true to original plans to serve the patient, recognizing the minimum criteria that are important to the patients and make their results comparable, communicating the relationship between process metrics and patient outcomes, recognizing the patients' life factors that contribute to their chronic illness, successfully identifying high-risk patients and integrating systematic protocols in varying sites. Health care improvement and VBHC cannot be achieved without the accountability and systematic learning offered by outcome measurement. Management, measurement, and ultimately success are inter-related. This paper describes the dynamic cultures and structures that facilitate teams' success for practitioners and patients through outcome measurement.

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